

**A Little Book About  
GASTROESOPHAGEAL  
REFLUX DISEASE**



**GERD**

**PHILADELPHIA COORDINATED HEALTH CARE**

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# Introduction

This booklet is designed for people supporting individuals with intellectual and developmental disabilities (I/DD).

Individuals with I/DD experience the same range of health concerns as individuals without. Gastroesophageal Reflux Disease (GERD), is one of the most common problems of the gastrointestinal tract which people experience. The severity of GERD can range from mild symptoms to being a precursor to esophageal cancer. Yet, GERD, is often not diagnosed or left untreated in individuals with I/DD. Individuals with I/DD may have other chronic health conditions which place them at further risk for developing GERD, such as posture problems, mobility issues, diet, and medications which may have gastric side effects.

To further complicate this situation, many individuals are unable to communicate verbally, making it easy for symptoms to go unnoticed and untreated at an early stage of the disease. It is vitally important that, in those instances, behavioral signs are documented and evaluated. Individuals with I/DD can also be helped through health promotion strategies; that is, by implementing those lifestyles and dietary recommendations which can help to control this disease.

This booklet contains information describing GERD, including the disease process, symptoms, testing, treatment options, complications, and signals of discomfort for those unable to verbally communicate. The purpose of this booklet is to help people better understand GERD, to recognize possible symptoms of GERD, to obtain proper treatment for GERD and thereby, improve the quality of life for individuals with GERD and developmental disabilities.

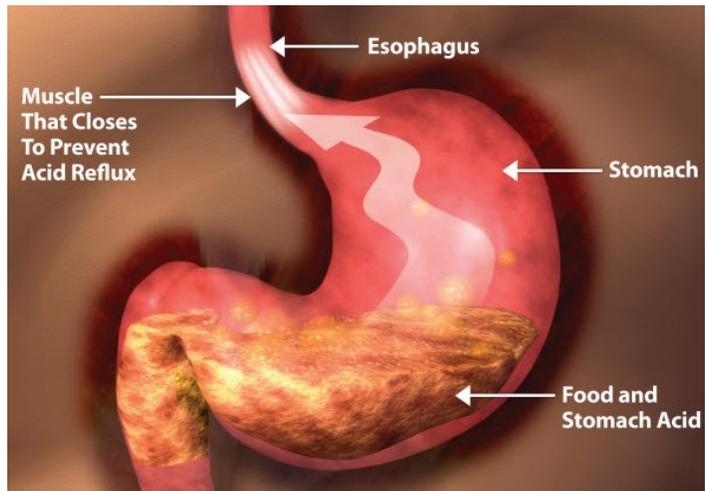
*If you think the person you support may have symptoms of GERD, seek medical attention.*

# BASIC BIOLOGICAL DEFINITIONS

**Esophagus-** means “carry food”; the esophagus is the muscular tube with a mucosal (moist skin-like) lining through which food moves from the back of the throat to the stomach.

**Lower Esophageal Sphincter (LES)-** the LES is a valve that opens to allow food to pass from the esophagus to the stomach and closes when food is not being swallowed.

**Stomach-** part of the gastrointestinal (GI) tract; a temporary storage tank where the chemical breakdown of proteins begins and in which food is converted into a creamy paste called chyme.



## What is Gastroesophageal Reflux?

**Gastroesophageal** refers to the stomach and the esophagus.

**Reflux** means to flow back or return.

**Gastroesophageal Reflux** is the return of the stomach's contents back into the esophagus.

**Normal digestion** occurs when the muscle connecting the esophagus with the stomach (LES) opens to allow food to pass into the stomach and closes to prevent food and acidic juices from flowing back into the esophagus.

**GERD** occurs when the muscle (LES) is weak, relaxes inappropriately, or opens under great pressure allowing the stomach's contents to flow back into the esophagus.



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# What Actually Happens?

The highly acidic contents of the stomach flow back into the esophagus. This causes the mucosal lining inside the esophagus to break down. Inflammation results from the exposure of the esophagus to the stomach acid.

## What Causes GERD

GERD occurs whenever there is:

1. inappropriate relaxation of the LES muscle due to
  - a) dietary factors- certain goods and beverages weaken the muscle function causing reflux and heartburn
    - chocolate
    - peppermint
    - fried/fatty foods
    - coffee
    - alcoholic beverages
  - b) cigarette smoking



2. decreased LES tone (muscle is weak) due to
  - a) disorders of the GI tract which slow mobility
  - b) an incompetent sphincter-valve does not work as it should; weak closure

3. increased intra-abdominal pressure due to
  - a) pregnancy
  - b) overweight
  - c) tight fitting clothes
  - d) some postures

4. increased volume of the stomach
  - a) large consumption of food at one sitting
  - b) gas in stomach
  - c) backup in blockage of the intestinal tract
  - d) backup from immobility of the intestinal tract



## Is All GERD The Same?

The disease process is the same, but the degree of inflammation and the extent of the destruction on the lining depends on:

1. The number of reflux episodes
2. The length of exposure time
3. The acidity of the contents

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# What Are The Symptoms?

Most people with GERD experience one or more of the following:

1. heartburn (the most common symptom; referred to as acid indigestion) feels like a burning chest pain beginning behind the breast bone and moving upward to the neck and throat. Many describe it as food coming back into the mouth leaving an acidic or bitter taste;

*The sensation can last as long as two hours and is often worse after eating. It can result from lying down or bending over. Relief sometimes can be achieved by standing upright or by taking over the counter antacids (i.e. "Tums" or "Rolaids"). This sensation often is confused with the pain associated with heart disease or a heart attack.*

2. frequent belching or burping;
3. chest pain that comes and goes;
4. regurgitation (partially digested food comes up from stomach into throat/mouth);
5. painful swallowing (odynophagia);
6. difficulty swallowing (Dysphagia);
7. excessive saliva (hypersalivation);
8. bad breath, particularly in the morning (halitosis);
9. frequent coughing;
10. awakening from a sound sleep with a sudden coughing episode.



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# How Is GERD Diagnosed



A person experiencing any combination of the previously noted symptoms should speak with their physician and be aware of the following issues that should be discussed:

## 1. **Medical history**

a) assess “heart burn” pain to determine the cause and course of its development

1. *When did it start?*
2. *When does it occur?*
3. *What relieves it?*
4. *Why do you think it might be happening?*

b) determine usual dietary patterns (foods eaten, amounts, and timing of meals)

## 2. **Esophagoscopy**

a procedure used to look inside the esophagus; a flexible tube (an endoscope) is inserted into the throat and down the esophagus; this test helps to detect erosion, inflammation, swelling (edema), and bleeding.

## 3. **Barium Swallow (also referred to as an Upper GI):**

a procedure used to detect the shape of the esophagus and any structural or sphincter (valve) abnormalities; it is also used to rule out peptic ulcers; the individual swallows a barium mixture (chalky substance) and then a series of pictures are taken under fluoroscopy; the barium aids the visualization of abnormalities.

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# How Is GERD Diagnosed (continued)

## 4. Esophageal Manometry:

a procedure which measures the movement in the esophagus (esophagus motility) and the resting pressure of the lower esophageal sphincter (valve); a tube is placed into the individual's mouth or nose and guided into the esophagus and stomach for pressure recording.

## 5. pH Monitoring (Esophageal acidity test):

a procedure which evaluates the competence of the lower esophageal sphincter by measuring esophageal acidity for 24 hours; a tube is placed through the nose into the esophagus; acid levels are monitored for 24 hours; the individual is asked to write down all activities performed during that period.

## 6. Gastroesophageal Reflux Scan:

a procedure which detects reflux across the gastroesophageal junction; the individual takes an oral mixture containing a radioactive substance and is positioned lying down while wearing an abdominal binder; as the binder is inflated, a camera takes pictures of the gastroesophageal area for 30 to 60 minutes.



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# What Are The Treatment Options?

## Lifestyle and Dietary Changes

1. Avoid foods and beverages that can weaken the muscle



- chocolate
- peppermint
- fatty foods
- coffee
- alcoholic beverages

2. Avoid foods and beverages that can irritate a damaged esophageal lining

- citrus fruits and juices
- tomato products
- heavy seasonings & spicy foods



3. Decrease the size of portions at a mealtime (eat smaller, more frequent meals rather than 2-3 large meals per day)

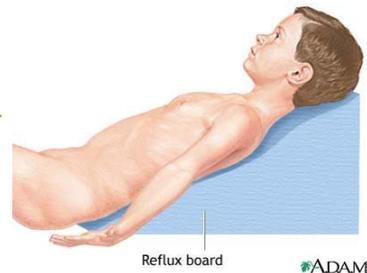
4. Eat meals at least 2-3 hours before bedtime (do not lie down immediately after eating any meal)



5. If overweight, lose weight

6. Do not smoke cigarettes

7. Elevate the head of the bed on 6 inch blocks or sleep on a specially designed wedge (allows for gravity to minimize reflux of stomach contents into the esophagus); if using a hospital bed, elevate the head of the bed to a 30 to 40 degree angle



8. Avoid tight-fitting clothes and belts around the midsection

9. Avoid activities that require considerable bending, stooping, (i.e. gardening, picking things off the floor, tying shoes, sitting slumped over in a chair)

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# Medical Management

## 1. Medications

- a) Antacids– over the counter  
Maalox, Tums, Rolaids
- b) H<sub>2</sub> Blockers- reduce acid secretion in the stomach (prescription)
  - cimetidine (Tagamet)
  - famotidine (Pepcid)
  - nizatidine (Axid)
  - ranitidine (Zantac)
- c) Proton Pump (Acid Pump) Inhibitor-reduces digestive acid more than H<sub>2</sub> blockers (prescription)
  - omeprazole (Prilosec)
  - lansoprazole (Prevacid)
  - rabeprazole (Aciphex)
  - esomeprazole (Nexium)
  - pantoprazole (Prontonix)
- d) Increase the rate of stomach emptying



2. Surgical Intervention- a small number of people with GERD may need surgery because of severe reflux and poor response to medical treatment; surgery should not be considered until all other measures have been attempted.

## Goals of Treatment

1. Minimize symptoms
2. Decrease the amount of reflux
3. Reduce the damage to the lining of the esophagus from Refluxed materials.

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# What Are Some Complications of Untreated or Long-Term GERD?

1. **Esophagitis:** occurs as a result of too much stomach acid in the esophagus; may cause esophageal bleeding or ulcers
2. **Esophageal strictures:** narrowing of the esophagus that may occur due to chronic scarring
3. **Barrett's Esophagus:** severe damage to the lining of the esophagus; may be a precursor to esophageal cancer
4. **Pulmonary Aspiration:** stomach contents enter the lungs



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# Why Is There A High Incidence Of GERD In Individuals With I/DD

We see an increased occurrence of GERD due to the following issues:

1. **Immobility and positioning-** many individuals have a history of spending a great deal of time in a lying position even immediately after eating; immobility decreases muscle tone, slows movement of food through the digestive tract
2. **Abnormal postures-** scoliosis, kyphosis, spasticity of abdominal muscles can create pressure on sphincter (valve)



3. **Central Nervous System (CNS) dysfunction-** esophageal motility and LES function are regulated by the autonomic nervous system; those individuals with severe CNS dysfunction may have esophageal motility problems as well as LES dysfunction
4. **Medication use-** many medications can delay gastric emptying, relax the lower esophageal sphincter, slow esophageal motility, decrease saliva, or directly irritate the esophagus

*Some examples (not as an inclusive list)*

- *Theophylline (Theo-Dur)*
- *Calcium channel blockers*
- *Meperidine (Demerol)*
- *Diazepam (Valium)*



*Always check with physician or pharmacist regarding side effects of medications.*

5. **Excessive drooling-** saliva neutralizes stomach acids and this protective mechanism is lost during drooling

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## Areas of Concern For Individuals with Limited Communication Skills

For many individuals with an intellectual developmental disability, communication skills may be limited. We should pay special attention to the following signs and discuss the possibility of gastroesophageal reflux with the primary physician.

- Drooling
- Meal refusals beyond the occasional occurrence
- Unexplained weight loss; individuals who remain significantly underweight even with high caloric intake
- Coughing/agitation during the night
- Crying/irritability within 30 minutes of meal time or during the night
- Night time awakening and seeking water/milk to soothe burning
- Self injurious behavior
- Change in complete blood cell count (lab results will show drops in red blood cells, hemoglobin and hematocrit levels if there is bleeding from the lining of the esophagus or stomach)
- Hands in mouth
- PICA behaviors (craving to ingest any material not fit for food, e.g. starch, dirt, clay, wood, paper, plaster, cigarette butts)
- Rumination (bringing up previously swallowed food and re-chewing it) or periods of vomiting
- Chewing and swallowing movements outside of meal time
- Body posturing-stiffening to relieve pain
- Noisy or wet respirations/asthma attacks
- Holding breath
- For those individuals with feeding tubes, formula in the back of the throat or formula on the breath
- History of antipsychotic medication use; current use of medications which have the side effect of relaxing the smooth muscle or delaying stomach emptying

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### **PCHC Mission Statement**

Philadelphia Coordinated Health Care's mission is to enhance access to community physical and mental health care through education, public health outreach, advocacy and empowerment as well as to improve health care outcomes for individuals with intellectual and developmental disabilities (I/DD).

### **Guiding Principle**

It is more important than ever, in the current health care environment, that we focus on integrated health care so that people with I/DD achieve wellness.



**A Core Program of**



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